



## QUARTER ONE 2018



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## Table of Contents

Executive Summary.....	3
A. Introduction.....	3
B. Objectives.....	4
i. Prevention.....	4
ii. Protection.....	4
iii. Equity and non-discrimination.....	6
iv. Research and data collection.....	7
C. Media coverage on albinism.....	7
D. Status of PWA.....	9
E. International links.....	9
F. Quarter 2 outlook.....	9
G. Annex -Extracts from the family visits.....	10
a) A happy family with a loving albino dad.....	10
b) Sarah drops out of school due to stigma.....	10
c) Fear to access medical facility.....	11
H. Call to action.....	11

## Executive Summary

In our pursuit to fulfill the objective of the strategic plan 2018-2020, Albinism Umbrella has undertaken various activities under the main themes of protection, prevention, research and Equity and non-discrimination. Under prevention, we have visited 14 homes in this quarter sensitizing the parents to children with albinism as well as provision of sunscreens to PWA.

On the theme of protection, a batch of 60 tins of 250g of sunshield shear butter sunscreen was produced with a donation from a team in Germany upon the visiting photojournalist Antonino Condorelli. Furthermore, 40 VHT (Village Health Team) were trained about albinism revealing that 95% of them had no idea of what albinism is and its causes. The training was done in support of Care for Uganda, a UK based charity working in Luweero district

To ensure equity and non-discrimination, awareness has continued to be done through the media where CBS radio provided a three months' awareness message about health, education and the general public calling upon parents and the public to embrace albinism as a genetic condition not as the known myths. This advert ran on 89.2 FM for this quarter.

The Parliamentary fundraising for the albinism center raised seventy-five million up from thirty-five of last year. This makes a total of 110m which will be used to secure land for the center.

Three schools were visited to provide basic information to teachers of children with albinism two schools were in Wakiso district while one was in Mukono district.

Albinism Umbrella carries out research and media focus about albinism. To this end, a total of five students have enrolled for university studies at Makerere University making it easier for other parents to have visible examples of success. One student undertaking Bachelor in Education is selling sweets to maintain her stay at the university.

In the second quarter, more training of VHTs, media awareness and the celebration of the international Albinism Awareness day are to critical activities.

### A. Introduction.

The first quarter has been good as we set foot on achieving our strategic objectives. Albinism umbrella has continued to be heard and its advocacy for PWA social inclusion is steadily reaching more people. The main activities undertaken in this quarter include parliamentary fundraising walk, home visits, radio awareness messages and other media engagements.

We set out to increase outreach of our messages of non-discrimination and acceptance for PWA. Schools and health personnel were central for the past quarter as focus audience for PWA. AU set out to widen its base by contacting different organizations with similar objectives to broaden our advocacy platforms.

As per the strategic plan 2018-2020, the objectives below have been used to guide our activities.

## Strategic objectives

1. To establish the status of persons living with albinism in Uganda and address the gaps identified
2. To establish a basic health care delivery program which will focus on providing health education about sun protection measures for persons with albinism, counselling and management of sun related skin problem
3. To reduce the levels of ignorance and stigma among persons living with albinism and the society
4. To help provide legal services and support the distressed persons through increasing visibility and partnerships

## B. Objectives

### i. Prevention

*To establish the status of persons living with albinism in Uganda and address the gaps identified*

- a) AU has sought support from development partners to undertake a national situation analysis of person with albinism in Uganda. There are considerable positive strides towards a national situation analysis.
- b) AU has continued to **visit different PWA in their homes to identify actual needs per home. 14 homes were visited in the first quarter** and the major challenge continues to be stigma, discrimination and poverty. During these visits, **sunscreens locally produced were distributed, counselling support given** to those who needed it and **encouragement to take up income generating activities.**

### ii. Protection.

*To establish a basic health care delivery program which will focus on providing health education about sun protection measures for persons with albinism*

Under this objective two main activities have been promised.

- a) The production of local sun screen
- b) Health education on how to prevent skin cancer.

#### **a) Local sun screen production.**

During this quarter, we were able to produce the first batch of 60 bottles of 250g each with the support from Germany. Antonino Condorell, a visiting photojournalist made his maiden trip to Africa on a mission to create awareness about albinism in Africa to Europe and seek for support to empower the PWA.



Dr. Betty and Olive Namutebi locally manufacturing the shear butter crèmes.

### **b) Health education**

This aspect focuses on sensitization of health related personnel about albinism. The condition is hereditary and this truth must be disseminated to avert cultural mis-information. The target audience are village health teams, health personnel like mid wives, training institutes and other policy makers and implementers of various programs.

In Q1, one training of VHT in Bbowa was done. 40 VHT were trained about albinism. It is important to know that, 95% of them had no idea of what albinism is and its causes. The training was done in support of Care for Uganda, a UK based charity working in Luweero district.



A village health team from Bbowa and surrounding sub counties who attended the albinism awareness training at Care for Uganda offices in Uganda.

iii. Equity and non-discrimination.

*To reduce the levels of ignorance and stigma among persons living with albinism and the society*

This is a core objective of AU and its success will go a long way in amplifying the PWA conditions in the country. To this end, AU has continued to its pursuit of an albinism center through the second Parliamentary fundraising walk held on 21<sup>st</sup> January 2018.

**a) Fundraising walk for Albinism Center.**

This walk was a great success raising seventy-five million(75M) shillings up from thirty-five million (35M) of 2017. This makes a total of one hundred ten million (110M) which should be sufficient to find the land for this project. Many individuals supported the cause compared to companies.

**b) School visits.**

Education is a key to success. Many children with albinism have not had a chance to attend school due to various reasons like bullying, teacher inability to guide them, parent's negligence and derogative name calling. AU resolved to create awareness in schools as a way to maintain those in schools, encourage parents to enroll children no yet in school and make an enabling environment. Three schools were visited have been visited so far.

- Cambridge Nursery school in Matugga where Benna Assimwe is in top class and greatly suffers with short sightedness.
- Joyous Educational centre in Wakiso where Olin Waako has attended school for the past three years. He is now in primary one.
- St Paul's primary school in Nakifuma where Macklean Nanteza and BennyHinn Sengendo attend school. The teachers are helpful and sit them at the front. The school administration has allowed them to wear hats all the time.



BennyHinn and Macklean seated at the front of the class wearing their hats. St Mary's Nursery and day care center in Nakifuma , Mukono district.

#### iv. Research and data collection.

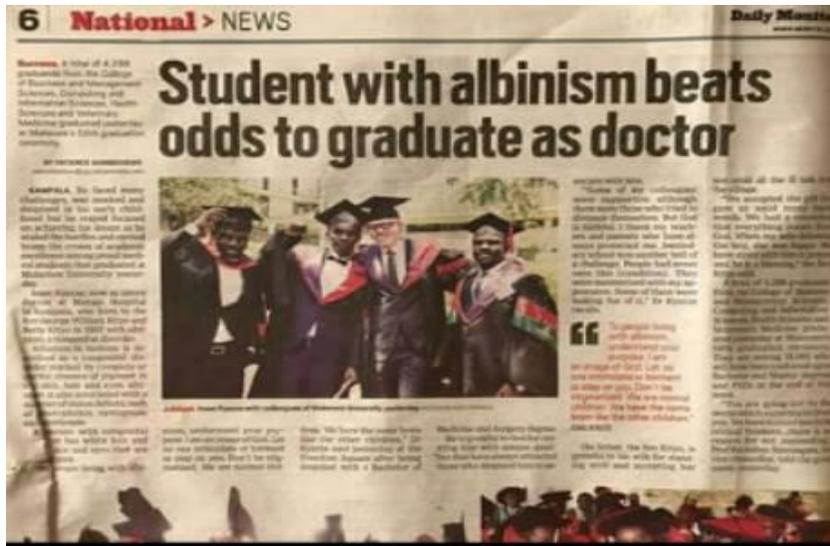
To change society attitudes and perspectives about the albinism condition, media plays a critical role. The Umbrella continues to make a presence in different media channels to raise awareness.

- In this quarter, we were able to have an awareness message ran on **CBS radio** for three months. Central Broadcasting Service is one of the leading brands in this space. It is a cultural based radio station for the Buganda kingdom.
- The Executive Director of AU was hosted on **NTV on 26th January** featuring as the big story of the day. [youtube.com/watch?v=FLeRoOLMIto ...](https://www.youtube.com/watch?v=FLeRoOLMIto...)
- Olive Namutebi was also part of the panel of **NBS** television prior to the Parliament week on Monday 15th January with Assistant Director Communication & Public Affairs at Parliament Ms. Helen Kaweesa.
- **Power FM, 104.1** is religious based radio station hosted Dr. Betty Udongo and myself on the Fahrenheit show aired every Saturday for two hours. On 2<sup>nd</sup> February 2018, we discussed process of the local sunscreen production and other non-discrimination awareness messages during the talks show.

#### C. Media coverage on albinism

There is need to provide guidance to journalist on how to write about albinism. Due to the high levels of ignorance about the condition, mis-information needs to be addressed. For instance, there is no known relationship of dental health to albinism as reported in the case of Diana Nabirye.

- Diana Nabirye struggling with poor eye sight and dropped out school. It is not true that albinism has any medical link to dental health.
- *Daily Monitor 22<sup>nd</sup> February 2018.*
- Pan African Parliament, Isaac Mwaura delivers a report where records for Uganda are inaccurate. This calls for accurate data on albinism in Uganda. *New Vision Monday 12<sup>th</sup> March, 2018*
- Nalubinga, a Mass Communication student at Islamic University in Uganda defender the rights of PWA. *Daily Monitor 21<sup>st</sup> March 2018*
- A medical doctor graduated in the recent Makerere University while a pupil excels at PLE from Nakaseke district.



- Akello fights for three children with albinism, the scarcity of sunscreen made her trek from Oyam to Gulu to get this rare jewel. [www.sunrise.ug/news/201803/albinos-woes-government-action](http://www.sunrise.ug/news/201803/albinos-woes-government-action).
- Namono Dorothy dropped out school and became a mother at the age of 16 years. Her son Jeremiah has albinism and Frank the father has denied responsibility and is in hiding. *Saturday Vision 31<sup>st</sup> March 2018.*



## D. Status of PWA

### Students at higher institutions

- There are five students with albinism at Makerere University who have joined this academic year.  
Two of these have undertaken a Bachelor of Education, three Bachelor of law and one is under the Social work. Ms. Carol Makene who visited Umbrella offices faces a sight challenge and her friends help to read on the board as she writes. She is one of those under Education and **sells sweets as a means to support her**. The Arlington academy supports her with school fees while the return on sweets is her upkeep.
- There is increasing need for school fees. More alarming need are students at secondary level who have overcome the main huddle of primary school. However, efforts to empower the parents have not yielded fruit.  
**Refer to annex for other examples**

## E. International links

Photojournalist from Germany.

AU has opened up its doors for students, photo journalist who are seeking information regarding albinism. Each year we host one or two of these pursuing the uniqueness of albinism in Africa. In January we hosted Antonino Condorelli in pursuit of an albino project aimed at creating awareness about Albinism in Africa. Antonino is to contact the European Parliament to show the lives of PWA in Africa through photography and perhaps any support may come through. For further info [www.antoninocondorelli.com](http://www.antoninocondorelli.com)

## F. Quarter 2 outlook.

In the second quarter Albinism Umbrella will among other activities undertake the following.

- Develop a press kit.
- IAAD celebration in Mbale
- Sign MoU with Equal Opportunity Commission
- Visit more schools
- Media campaign on albinism awareness.
- Continue networking with emphasis on health platforms

## G. Annex -Extracts from the family visits.

### a) A happy family with a loving albino dad.



Paul Kalika 27, is a proud father of four children and husband to Sharifa.

He is married to Sharifa Kalika and recalls the rough times of dating. His in laws initially resisted their relationship due to stigma. Love knows no borders; they were bound to be married in a catholic church four years later. Paul is an artist and a farmer. He has built a home for his family on almost one acre of land in Wakiso district. He envisions doing more agriculture

Paul's mother abandoned him at the funeral of his father and never saw her again. He was raised by his grandmother who cared and loved him. Paul recalls with vivid memory of the day he was kidnapped in disguise of customers of his music. He was picked up from Busega and abandoned in Rakai district after his kidnappers failed to agree on something.

### b) Sarah drops out of school due to stigma.



Sarah holds her son at their home in Kakiri.

Sarah Naluwoza got married to Saazi Vincent as a way to mitigate stigma. She believed no one could appreciate her except a fellow person with albinism. Vincent is a police officer attached to Kakiri police station. He is too dropped out of school due to stigma. He is a jolly man helping others whenever he can. The family is helping other two children.

Sarah suffered a lot of discrimination which forced her out of school. The Head teacher knew her sight challenges while the class teacher did not want her to sit at the front of the class.

Often times when the Head teacher passed by, Sarah was brought to sit at the front of the class but soon sent back upon his departure. This went on for long until she could not bear and decided to drop out.

Her grandmother who cared enough took her to the school for the blind in Mukono where she learnt tailoring a life skill that supports the family now

“My mum and her relatives never loved me, and they discriminated me all my life” She laments. The couple with their two children live in Kamuli -Kakiri on Hoima Road, Wakiso district. *Source. Albinism Umbrella 2018*

#### c) Fear to access medical facility

Lillian Nakavuma, 24 years, a mother of two daughters recalls the dreadful moments of attending an antinental clinic in one health facility where the nurse refused to attend to her. “I was pushed away, with scolds of why I dared to become pregnant” This was her first pregnancy, fathered by a shamba boy who later returned to his homeland in Rwanda. The second daughter was due to rape and she never dared to go back to that health facility but found solace in a nearby clinic where the nurse accorded her great medical help.

Lillian, struggling with skin cancer lives with a grandmother as the only relative she knows on earth. Her mother abandoned her shortly after being weaned while the father fled upon the news of her birth. The grandmother equally wonders why her daughter has never returned nor heard from her since Lillian was weaned. *Source. Albinism Umbrella 2018.*

#### H. Call to action

2018 Albinism Umbrella is to focus on local production of sunscreens. The concept is based on an already approved formula and the trials are successful.

Please join us to make this a reality and empower PWA in Uganda and Africa as a whole.

- Provide financial support to carry out tests for the standard and quality mark from Uganda National Bureau of Standards UNBS and National Drug Authority at a cost Ushs 10m. (ten million shillings only)
- Recommend credible scientists to test the sun protection factor (SPF) of each oil used in the lotion and other technical support.
- \$100 can currently make 30 bottles of 250g each for the desperate ones who will not wait for certification.
- Come on board for the albinism school awareness program by printing materials, provision of transport for the team and supporting the radio talk shows.

#### **Contact information.**

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